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ABSTRACT

The fifth of a series of brief reports on the study of mental retardation in a Canadian province covers a period of approximately cne year (September, 1969, through November, 1970). The period under review is primarily one of data gathering with the emphasis on the adequacy of the sampling procedure, follow up of incomplete interviews, and tapping of the sample for opinions of the mentally handicapped, as members of families and society at large. The study itself is an attempt to investigate the prevalence of mental retardation in a geographically defined Canadian population (Prince Edward Island) and to devise a criteria with maximum flexibility for use in social and health planning in the field of mental retardation. The document includes information on preparation of data, methodclogical issues, staff and facilities. (CD)

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MENTAL RETARDATION IN A CANADIAN PROVINCE

Report No.5

for the period September 1, 1969 to November 1, 1970

C.W. Portal-Foster

Canadian Council on Social Development
55 Parkdale Avenue
Ottawa 3, Ontario

December, 1970

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U.S. DEPARTMENT OF HEALTH, EDUCATION & WELFARE
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MENTAL RETARDATION IN A CANADIAN PROVINCE

A Report for the Period:

September 1, 1969 to November 1, 1970

Report No. 5

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December, 1970

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PREFACE

This is the fifth of a series of brief reports

on the study, Mental Retardation in a Canadian Province

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MENTAL RETARDATION IN A CANADIAN PROVINCE

Introduction

This report covers the period September 1, 1969, to November 1, 1970, and is the fifth in a series intended to cover the development, execution and findings of the study. The period under review was primarily one of data gathering and initial steps in the preparation of data for analysis, as carried out from field offices in Prince Edward Island. The report places emphasis on the adequacy of the sampling procedure - as shown by preliminary data - follow-up of incomplete interviews and refusals and the tapping of the sample for opinions of the mentally retarded as members of families and society at large.

The Study

The study itself is an attempt to test hypotheses related to the prevalence of mental retardation in a geographically defined Canadian population. In addition, an objective of the study is to devise definitional criteria with maximum flexibility for use in social and health planning in the field of mental retardation. It is central to the objectives of the study that inclusion of subjects in the target sub-sample should adhere to criteria related to their level of functioning in their home community environments. Also, that inclusion of an individual in the target sub-sample should reflect the possible purpose to which prevalence information may be applied. This assumes that an individual's needs for services are a function of his environment, externally as well as internally. Hypotheses of the study, in addition to basic assumptions or postulates and aspects of the research design, have been included in previous reports on the study.

The area of study is Prince Edward Island, the smallest of the Canadian provinces. Prince, Queens and Kings - the three counties of the province - have a combined population of approximately 110,000 in an area of 2,184 square miles. The Island is located in the lower Gulf of the St. Lawrence River and is an area predominantly of small villages and farms. There are only two communities of significant size, the largest of which has a population somewhat less than 20,000. The people are primarily of British heritage, with a sizeable minority of Acadian French in the western area of the province. Despite its great potential, Prince Edward Island remains one of the more economically disadvantaged areas of Canada.

The Sample

The research design specifies that a stratified sample of 4.15 per cent, or 4,513 persons, be drawn from the total population of the province. From this sample, a sub-sample of mentally retarded will be designated and their data examined. The sample is assumed sufficiently large to yield data cells of the appropriate size for statistical manipulation.

The total sample of 4,513 subjects has been allocated to the three counties of the province according to their portion of the total population. Within counties, six population strata, including rural and five ranges of community size, have been designated. Table I gives details of the required sample by county for each population strata. It should be noted that Kings county has no communities in the population range 10,000 plus.

The rural population was sampled by county using random selection of grids from a 1/50,000 scale map. A total of 6,682 grids covered the total land area of the province. The procedure of using random selection of grids

to sample the rural and rural non-farm population procured a highly representative sample of the rural population, as will be shown by the subsequent discussion. The procedure does, however, present disadvantages

TABLE I

Stratified Sample by Counties and Populations of Communities

County	Population group	Population of group	Number of Communities		Sampling ratio	Sample size
			County	Sample		
Prince	10,000+	10,042	1	1	1:24	417
Queens		18,427	1	1	1:24	765
Prince	1,000 to	2,441	2	2	1:24	100
Queens	10'000	4,478	2	2	1:24	186
Kings		2,732	2	2	1:24	114
Prince	500 to	4,573	6	3	1:12	202
Queens	1,000	874	1	1	1:24	36
Kings		1,348	2	2	1:24	56
Prince	300 to	725	2	1	1:12	33
Queens	500	754	2	2	1:24	31
Kings		790	2	2	1:24	32
Prince	200 to	3,290	14	7	1:12	138
Queens	300	2,968	14	7	1:12	133
Kings		1,876	7	7	1:24	63
Prince	Rural	21,612	-	-	1:24	896
Queens		19,926	-	-	1:24	827
Kings		11,652	-	-	1:24	484

which are, in turn, probably functions of several factors, including the type of terrain, the economic base of the area, distribution of the inhabitants and grid size.

The small grid size of .6 square miles may have accounted for many of the approximately two-thirds of selected grids being vacant. In many instances though, grids were vacant due to the exodus of people to the larger communities of Prince Edward Island and elsewhere. All grids were checked by an on-site inspection with a resulting heavy demand on time and budget. Since complete interview coverage of grids was attempted, the field work was vulnerable to unco-operative subjects and to persons who refused outright. Where problems of this nature arose, the loss of successful interviews was minimized due to the limited number of people in small grids who could be contacted with adverse comments.

Field experience, in rural as well as village and urban situations, confirmed the correctness of the earlier decision to avoid media and other forms of publicity so knowledgeable interviewers could present the study to subjects and react immediately to questions that arose. The introduction of a study to a population remains a difficult methodological issue due to the diversity of research situations encountered and the absence of criteria that can be applied across the wide range of study objectives and circumstances.

The rationale of sampling ratios and the selection of communities has been outlined in more detail in previous reports on the study.

A preliminary assessment of sampling procedures was carried out in September, 1969, using data from the initial 511 households contacted. At that point in time, no alterations in procedure were indicated. Table II gives the total sample as projected from data then available. The projected sample was not significantly different at the .001 level from the 1966 census using the age/sex distributions as criteria.

TABLE II

Projected Total Sample and 1966 Census by Age Group

Age group	1966 Census Number	1966 Census Per Cent	Projected Sample Number	Projected Sample Per Cent
0 - 4	12,587	11.59	510	11.33
5 - 9	13,023	11.99	588	13.04
10 - 14	12,023	11.07	524	11.62
15 - 19	11,061	10.19	503	11.15
20 - 24	6,781	6.24	256	5.67
25 - 29	5,715	5.26	265	5.87
30 - 34	5,541	5.10	248	5.50
35 - 39	5,374	4.95	216	4.79
40 - 44	5,538	5.10	199	4.41
45 - 49	5,475	5.04	185	4.10
50 - 54	5,371	4.94	221	4.90
55 - 59	4,617	4.25	154	3.41
60 - 64	3,740	3.41	180	3.99
65 - 69	3,595	3.31	190	4.21
70 - 74	3,237	2.98	105	2.32
75+	4,857	4.47	165	3.65
Totals:	108,535	99.89	4,509	99.96

1966 Census data from DBS Bulletin No.92-610 (March, 1968)

As of November 1, 1970, approximately 99.75 per cent - or 4,502 of the 4,513 individuals designated for the sample - had been contacted. Field work has progressed in an easterly direction through the province, with fairly firm data now available in the composition of the Prince County sample. Table III shows the county sample and enables comparisons with the 1966 census. The ages of two male and two female subjects are unknown but their omission has only slight bearing on the interpretation of the data.

The final sample for Prince is 1,794, as opposed to the 1,786 designated by the research design. The final sample is 4.19 per cent of the county population. Contacting of households in communities was discontinued when the N attained fell within .5 households of the required sample size (household = 4.2 persons: Census 1966). Contacting of households in rural areas was discontinued when the N of 896 had been attained. The eight additional subjects are accounted for by the rounding of community and grids to complete households.

TABLE III

PRINCE COUNTY: Age/Sex Distributions by Totals and Per Cents for Total Population and Sample

Age	Population						Sample					
	M/F	%	M	%	F	%	M/F	%	M	%	F	%
0 - 4	5543	12.99	2808	6.58	2735	6.41	224	12.49	114	6.36	110	6.13
5 - 9	5604	13.13	2835	6.64	2769	6.49	226	12.60	130	7.25	96	5.35
10 - 14	4941	11.58	2496	5.85	2445	5.73	220	12.26	111	6.19	109	6.08
15 - 19	4383	10.27	2209	5.18	2174	5.09	184	10.26	97	5.41	87	4.85
20 - 24	2650	6.21	1422	3.33	1228	2.88	110	6.13	62.	3.46	48	2.68
25 - 29	2337	5.48	1194	2.80	1143	2.68	95	5.30	58	3.23	37	2.06
30 - 34	2347	5.50	1223	2.87	1124	2.63	88	4.91	39	2.17	49	2.73
35 - 39	2063	4.83	1061	2.49	1002	2.35	98	5.46	43	2.40	55	3.07
40 - 44	2074	4.86	1066	2.50	1008	2.36	66	3.68	28	1.56	38	2.12
45 - 49	1991	4.66	1005	2.35	986	2.31	79	4.40	43	2.40	36	2.01
50 - 54	1878	4.40	962	2.25	916	2.15	90	5.02	43	2.40	47	2.62
55 - 59	1663	3.90	898	2.10	765	1.79	66	3.68	31	1.73	35	1.95
60 - 64	1313	3.08	688	1.61	625	1.46	64	3.57	34	1.90	30	1.67
65 - 69	1251	2.93	631	1.48	620	1.45	59	3.29	32	1.78	27	1.51
70 - 74	1089	2.55	521	1.22	568	1.33	49	2.73	29	1.62	20	1.12
75+	1561	3.66	750	1.76	811	1.90	72	4.01	34	1.90	38	2.12
							4	.22	2	.11	2	.11
TOTALS:	42688	100.33	21769	51.01 (51.00)	20919	49.01 (49.00)	1794	100.01	930	51.87	864	48.18

There is not a statistically significant difference between the obtained sample and the census at the .001 for males, females, or male/female (t: male = 6.82; female = 5.02; m/f = 6.91; .001 = 4.015). Percentage point differences between the obtained sample and census data for the 48 age/sex categories (mf/age; m/age; f/age) range from .01 for mf/15-19 age to 1.18 for mf/40-44. Only two of the 48 categories differ more than 1.00 percentage points from the criteria. Mean differences for males and females are .33 and .55 respectively. This is somewhat improved over the earlier projection.

It appears evident that the final study sample will be highly representative of the total population of Prince Edward Island.

Refusals and Incomplete Interviews

The selection of appropriate subjects for inclusion in a study sample is indispensible to success in applied social research if inferences to larger populations are anticipated. The obtaining of data from individuals thus selected is an equally important companion issue, but one that is often much more difficult to resolve. Research designs, objectives and field conditions vary so widely that criteria for the adequacy of coverage must be set arbitrarily for individual studies. Little is known, it seems, of reasons for interview refusals, how adequate follow-up of difficult subjects can best be effected, or the consequences of omitting large blocks of data from subsequent analysis. A very adequate sample and good instrumentation may not, in fact, yield valid data if coverage is incomplete beyond reasonable limits. These issues seem additionally important within the context of the present study due to the length and complexity of the research battery and the inclusion of sometimes intimidating psychometric and social measures. An

attempt will be made in a subsequent report to clarify these questions as they have been encountered in the present work.

The possibility of attaining a high degree of interview coverage in Prince Edward Island using the present research design elicited a number of rather dismal projections. Nonetheless, in an earlier report in this series, the opinion was expressed that final refusals could be maintained within acceptable limits and, hopefully, well below ten per cent of individuals contacted.

The term "refusal" as used here does not include instances where interviews were not completed for medical, intellectual or related reasons unless the subject indicated that he did not wish to participate in the study. The term "refusal" indicates that the subject declined the total research battery or on whose behalf the interview was declined. A number of interviews remained incomplete due to the rejection of either of the two major instruments. These interviews are referred to as "incompletes" and apply only to subjects aged three or more. In addition, a larger number of subjects refused isolated items from one or more of the various sections of the research battery.

Reports on subjects who could not be successfully interviewed by members of the field staff raised the possibility that data of the group were important to study objectives. It appeared that many persons who refused interviews functioned at a below-average level and that this in turn was one of the causitive factors in their reluctance to be interviewed. This assumption, coupled with the knowledge that follow-up of every interview that had not been completed by field staff would present a prohibitive work load, led to a decision to concentrate effort in one county. A corrective factor, if necessary, could then be developed for application to data of the two remaining counties.

Prince was chosen for the more intensive follow-up since it was the first to receive complete coverage by field personnel. The study director contacted each of the 73 households in the county wherein one or more persons had refused one or more sections of the research battery. There were 167 persons or 9.3 per cent of the county sample in the 73 households. Initial contact was in the form of a registered letter outlining the purposes and techniques of the study and the method of selecting persons for interview. The letters were written individually and attempted to deal with issues raised by the subject when initially contacted by a member of the field staff. Finally, permission for a personal interview was requested and it was added that if this was not acceptable no further initiatives would be made on behalf of the study. Personal interviews occurred within a few days of the registered letter.

That the initial step in follow-up of problem interviews was a key to the success achieved, including acceptance of study objectives, seems indisputable, despite the considerable amount of time involved. It is necessary to weigh the disadvantages of the procedure against the assumed value of the large block of data involved. Follow-up was carefully calculated to attain success while avoiding a coercive taint with its numerous disadvantages, including destruction of rapport which had been established throughout the province. Remunerative aspects of interviewing were carefully avoided, although there was continuing misinterpretation of the name of the sponsoring agency. (The Canadian Welfare Council has recently changed its name to the Canadian Council on Social Development). This is an important issue in an area where 25 per cent of the population is said to live below the poverty level. Islanders are a proud people with an intense love of their province and interest in social progress. They will, with few exceptions, give freely of their time

to accommodate the requirements of a lengthy and complex interview despite difficulty in relating possible benefits directly to their immediate families. It is necessary, however, that basic information on the study be presented using appropriate terminology and that all questions be answered in a forthright manner.

In all cases, respondents received a further, though brief, letter acknowledging their participation and assistance.

Table IV presents data on the Prince sample and the disposition of interviews. Final results are expected to vary little, if any, from those shown. The refusal rate for the county as of this date is 3.2 per cent or 58 of the 1,794 persons contacted. Unsuccessful interviews in the rural area reached only 2.1 per cent while the city rate is 4.8. Almost half of the latter group are members of one family. A concerted follow-up effort was not undertaken due to conditions known to exist in the family.

TABLE IV

Prince County: The Sample and Interview Follow-up

Strata	Required N	Contacted N	Followed up	Disposition			Refusal rate %
				Completed	Refusal	Incomplete	
Rural	896	904	76	45	28	3	3.1
Town	473	472	31	17	10	4	2.1
City	417	418	60	38	20	2	4.8
TOTALS:	1786	1794	167	100	58	9	3.2

There are 58 refusals, of which 17 are minors or persons who did not make a decision on their own behalf. Likewise, 30 of the subjects successfully inter-

viewed during follow-up were either minors or other individuals who did not make their decisions independently.

Detailed data regarding the present status of follow-up procedures in the two eastern counties are not available at this date. However, it is improbable that the time schedule will permit a full examination of every issue that has arisen in the field. A final rate - considerably less than 10 per cent of refused interviews - seems assured for the total study sample.

Subjective judgment at this point in time appears to support earlier assumptions concerning interview techniques and appropriate procedures for follow-up.

Opinions of Mental Retardation

A fifteen item mail questionnaire has been used to tap community and family perceptions of the mentally retarded. It has been mailed, with a covering letter and self-addressed stamped envelope, to families that have completed the initial research battery.

The questionnaire is a seven-point check list of items related to the mentally retarded as family and community members. It solicits respondents opinions on the ability of the retarded to benefit from educational programmes, their potential for self-reliance, including economic independence, where they should receive care and whether or not the mentally retarded are really mentally ill.

Specific data concerning the rate of returns are not available at this point, but a preliminary examination shows that 35 to 40 per cent may be available for final analysis. Also, questionnaire returns appear to be related to a number of factors that may warrant examination for methodological purposes. Rate of return, for example, seems to bear a relationship of sex of interviewer and success of follow-up.

Preparation of Data

The preparation of data for analysis began in late summer with university students working full or part-time on coding.

The total coding protocol includes eleven machine cards, two of which relate to family units and households. The remaining cards are for respondents, although individual subjects do not require the total series. Babies, infants and older adults were administered part of the total research battery. The coding protocol is designed to facilitate item analysis of test scale items. Such analysis, it is thought, may reveal worthwhile information on the performance of a Canadian population to items that are essentially foreign in origin.

Methodological Issues

Numerous methodological issues have arisen during the field work phase of the project. Many of these, if closely examined, may reveal important directions for future applied social research, particularly in the field of mental retardation and mental health where complex and lengthy research batteries must be used.

Unlike clinical or laboratory researchers, field workers must encounter subjects in the latter's own environment. Interview conditions are often very difficult to control. Social restraints that usually prevail in various encounters are largely removed and the researcher finds himself very much in the subject's domain.

Academic qualifications of interviewers may not be as important as originally anticipated. Adequate training in the content area and with the research battery is important both from the research and economic points of view. Changes in the sequence of items or scoring of responses can constitute changes in the total

research design and must be closely controlled. While it is important that interviewers adhere closely to established procedures, it is necessary that they have sufficient flexibility to accommodate a very wide range of situations.

Sex of interviewers now appears to be one of the more important determinants of success as a field interviewer. There are indications, as yet not analyzed, that young women are much more successful in finding respondents, obtaining interviews and completing forms adequately. In this particular study, female personnel had, on an average, one year less academic training, but this deficiency seems unimportant in view of their greater understanding of the human elements involved, their understanding and acceptace of research principles, and their ability to work with precision. Tenacity and a greater tolerance of difficult working conditions also seem to be important attributes of female field personnel.

It is expected that problems of field research will be dealt with in greater detail in a subsequent report.

Staff

There have been sixteen field interviewers with the project since the beginning of operations in May 1969. Only one interviewer has worked continuously throughout the period and twelve of the sixteen were recruited locally.

The policy of employing university students for field interviewing has not, unfortunately, proven entirely satisfactory in the present situation. While students bring several advantages which are well known, the limited period they can devote to summer employment presents a severe restriction

where complex interviewing is involved. The period of full productivity was very short due to the required training period, time required to establish interviewers in the field and a further period for closing operations. The problem of obtaining interviews from fishermen and farmers during peak seasonal periods would not apply in many other research situations.

The preparing of research forms and coding was begun by six university students late in summer. This operation is continuing with a reduced staff.

Facilities

The Division of Mental Health of the Province has continued its co-operation and assistance throughout the period under review. Modern office facilities in both the major population centres of the province have been provided for the entire project staff without cost. By any measure, the assistance of the Division has been a very significant contribution to the success of the study.

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Dr. H.D. Beach, Department of Psychology, Dalhousie University, has provided consultative services to staff on several occasions during the period.

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Staff members of mental health and public health nursing clinics in various centres of the province have assisted study personnel in many ways and have thus contributed significantly to the success that has been attained.

Staff members of Sherwood Hospital, Charlottetown, and Prince County Health Centre, Summerside, have, through their congeniality and interest, added much to the pleasure of researching in an area far removed from one's home environment.

The most important acknowledgement of all perhaps, must be directed to the citizens of the province who have permitted outsiders to enter their homes and carry out lengthy interviews. In many instances, interviews were obtained at considerable inconvenience to respondents and often several appointments were required for individual families.

REPORTS AND PAPERS BASED ON THE STUDY

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2. _____, Butt; Dorcas Susan and Tate; Douglas L., Pilot Study and Design Development to September, 1968, Report No. 2, Mental Retardation in a Canadian Province, Ottawa: Canadian Welfare Council, Research Branch, 1968, pp.24.

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